

Statement of Charity Sunshine Tillemann-Dick
Committee on Energy and Commerce, Subcommittee on Health
“Improving America's Health: Examining Federal Research Efforts for Pulmonary
Hypertension and Chronic Pain”
December 8, 2005

Our lives are a race against ourselves – we struggle to replace fear with hope, selfishness with selflessness, ignorance with knowledge, apathy with action. And in this contest, it is the hope that the good inside us will prevail. But in May 2004, my life's race was no longer between my higher and baser self, but against time.

My story is typical of many who have suffered or who are suffering from PH. From the time I was a little girl, I was an excellent sprinter. We have old videos of me playing soccer, running to the ball and then slowing to a shuffle, hands on my waist, catching my breath. We weren't a particularly athletic family, so when I'd have trouble running back and forth on the basketball court or finishing allotted laps on swim team, I would blame it on a lack of physical activity in my life. So, when I was 18, I started working out – at least an hour a day, and sometimes three hours a day, four days a week. But still, when I stepped on a treadmill to run, I would quickly feel faint and stopped before something happened.

The climax of my pre-diagnosis drama came over a nine-month period of time when I experienced four syncopal – or fainting -- episodes spanning two continents. My first actual fainting spell came when I was crossing a street in Denver. I fainted in the middle of one of Denver's largest intersections. Three subsequent episodes were similarly dramatic; I never knew how unromantic fainting into a man's arms could be. I knew something was wrong; I just didn't know what it was. But I went on with my life. Doctors told me to do everything from increase my salt intake to lift my blood pressure to eat red meat to cure mild anemia. My parents had both experienced fainting spells around my age, so I hoped that perhaps, nothing was wrong.

When I returned home for a visit to Denver, the Mile High City, in the spring of 2004, I had some medical paperwork that needed to be filled out for the next year. The day before my appointment, I walked to my old college less than a mile away to go to the gym with my little brother, Corban, who was entering the Air Force Academy that summer. I had to stop every 25 feet or so, when I was too exhausted to go on without a rest. Seeing how tired I was from a simple walk, I toned down my workout, which I still couldn't complete. Finally, on our slightly downhill walk home, Corban, seeing something was obviously wrong, told me to wait under an oak tree four blocks from our home so he could run home and get the car. When he returned, I got it. “Charity, are you all right?” he asked. In a family of 11 children, the last thing anyone wants to be is an alarmist. But it was difficult to explain why at 20 years old with a clean bill of health and an exercise regiment that I kept with religious diligence for two years, I became weaker. I had to stop three to four times when climbing the stairs to my third story apartment in

Budapest. So, I told Corban that I had a doctor's appointment the next day and we'd see.

I went to the doctor's. It was a rather extensive list they had to check off, and Dr. Susan Wells did an excellent job. She first discussed my health with me. My arm's blood pressure was very low, so some of the explanations seemed logical for my problems. But as soon as she listened to my heart, she ordered an EKG. I wasn't wearing my contact lenses, but the tech's eyes seemed to pop open when the results were printed out. I hoped I was imagining. As I waited in the stark check up room, I heard the doctor talking about me and my accomplishments with someone for what seemed like a very long time. I knew that it was time to be either very flattered or very concerned. When Doctor Wells returned, she kindly informed me that there was a slight possibility that I was suffering from Primary Pulmonary Hypertension. She advised me not to look it up until the diagnosis was made. I thanked her and went on my way. Thinking about it, "primary," sounded alright. It comes first. "Pulmonary," whatever. Hypertension. That's me. I told my mother who, when we got home, looked it up in our medical encyclopedia. It wasn't there. I proceeded to our family computer room where I put it into a search engine. Some things matched up, but I certainly wasn't suffering from all of the symptoms yet. The prognosis didn't parse words. It said, "For those suffering from Pulmonary Hypertension, the prognosis is bleak. There are few effective treatments and patients typically die two to five years after diagnosis." I assure you that is an interesting prognosis for anyone to read.

In the next days and weeks, my family and my entire community grappled with how to deal with this disease, helping me to see a whole other range of societal problems. In the next months, I realized while my form of the condition, Idiopathic or Primary Pulmonary Hypertension, was very rare, that there were 100,000 Americans like me, living with a very literal death sentence. I was on a medical trial, but its benefits didn't last that long. By the end of the year, my arterial blood pressure was nine times higher than anyone who is alive should have. I took the last three weeks off of my studies at the conservatory and was given intravenous medication over the Christmas holiday. I was told that patients experienced jaw pain. At 2:00 a.m. I awoke, my face red and my temperature soaring. At that moment, I realized that until then, I had never experienced real pain. It was so intense, so searing, so unbearable that, had it not been so painful, would have been comic.

It seems simple enough to isolate PH patients' experience to the medical drama, but we have to go on living our very real lives. With those I don't know well, I deal with the social awkwardness of the really of not being able to keep up, only going somewhere with elevator access, not going out to eat, and people thinking I'm clutchy for my never putting down my purse. Occasionally people try to take it from me when I get up to sing or make a presentation. They don't realize that there is a line connecting my heart to the pump in that purse which must dispense medicine to me 24 hours a day. Patients are overlooked for promotions, and I have been overlooked for castings because directors or employers often have valid concerns about medical concerns interfering with productivity or the final production. We hope to live as normal a life as is possible, but in reality, our

lives are being cut tragically short, every day. I am in relatively good health, but a chest x-ray taken Tuesday indicates that even with the very invasive treatments I am undergoing, my heart continues to get larger.

While I feel relatively good, I don't know how much more time hope can keep my body alive. Without action on your part, thousands of American lives, including mine, will be lost, fighting this battle alone. Diagnosis with a life-threatening disease is not something I would have ever asked for. But I know that with funding, we can make this disease, first, manageable, like most forms of cancer and AIDS and that soon, we will find a cure. (A situation has to be pretty desperate when anyone would hope their condition would be as manageable as AIDS or cancer!) In our race against time, every breakthrough is a victory – as we approach treatments we all get closer to winning our race against time, and with your action, we can cure Pulmonary Hypertension.

Please do everything in your power to add Pulmonary Hypertension to that list of conditions that will be at least manageable if not cured in the next few years. This bill is a starting point that will shed light on this life-threatening disease and give thousands of people the hope they need and deserve.

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